



EFFECTIVE COMMUNITY COLLABORATIONS

Balancing Empiricism and Local Cultural Knowledge in the Design of Prevention Research

Philip A. Fisher and Thomas J. Ball

ABSTRACT *Prevention research aims to address health and social problems via systematic strategies for affecting and documenting change. To produce meaningful and lasting results at the level of the community, prevention research frequently requires investigators to reevaluate the boundaries that have traditionally separated them from the subjects of their investigations. New tools and techniques are required to facilitate collaboration between researchers and communities while maintaining scientific rigor. This article describes the tribal participatory research approach, which was developed to facilitate culturally centered prevention research in American Indian and Alaska Native communities. This approach is discussed within the broader context of community-based participatory research, an increasingly prevalent paradigm in the prevention field. Strengths and limitations of the approach used in the study are presented.*

KEYWORDS *American Indian and Alaska Native, Community-based participatory research.*

INTRODUCTION

Since the 1970s, prevention science has emerged as a powerful tool for combating health and social problems. Along with intervention strategies have come research methodologies for evaluating the effectiveness of these interventions, including the use of randomized clinical trials. Much of the seminal work in the prevention field has emanated from academic settings and has been largely investigator driven.¹ Derived from a logical positivistic scientific tradition, investigator-driven approaches emphasize the independent and objective perspective of the scientist. Investigator-driven approaches in prevention research have many merits, including high levels of fidelity in the implementation of interventions and the use of state-of-the-art evaluation designs. These approaches have significantly impacted public health and have resulted in the wide dissemination of evidence-based programs in community settings.

In recent years, approaches that emanate from within communities or that are community centered have also become prevalent.² In contrast to investigator-driven methods, community-based participatory research (CBPR) tends to be less focused on widespread generalizability and diffusion. Rather, an emphasis is placed upon the empowerment of individuals and communities through the research process.²⁻⁴ Therefore, community members are centrally involved in all aspects of the prevention

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research process—including the design, implementation, and evaluation of interventions. Moreover, the separation between researchers and community members is deemphasized. Incorporating elements of hermeneutic epistemology, value is placed on the co-construction of meaning by community members and researchers; as such, they must collaborate to achieve successful outcomes.

The roots of CBPR lie in the work of Lewin, who used the term “action research” to describe an approach that stressed cycles of action and reflection involving researchers and research participants.⁵⁻⁷ In the 1980s, these methods were applied to studies specifically oriented toward social change in an approach called participatory action research (PAR).⁸⁻¹¹ PAR incorporates the values and beliefs of research participants as the core of scientific inquiry.¹⁰ According to Greenwood and Levin, PAR conceptualizes research, first and foremost, as increasing participants’ self-determination.¹² In addition, PAR treats the diverse experiences of individuals (i.e., heterogeneity) as opportunities to enrich (rather than challenges to) the research.

Whereas PAR typically focuses on change at the individual level, CBPR emphasizes change at the community level. Researcher–community collaborations have the potential to be problematic because of a mutual lack of understanding about roles, priorities, responsibilities, values, and perspectives across the two groups. CBPR can facilitate greater clarity in these partnerships through the establishment of specific principles to guide the process.¹³ For example, Potvin et al. described the following elements of CBPR: (a) the integration of community people and researchers as equal partners in every project phase; (b) the structural and functional integration of the intervention and evaluation research components; (c) a flexible agenda that is responsive to demands from the broader environment; and (d) the creation of a project that presents learning opportunities.¹⁴ Similarly, Metzler et al. described CBPR as including joint ownership over decision-making, defining principles of collaboration, establishing research priorities, and securing funding.¹⁵

Within the CBPR approach, the input of key community stakeholders is solicited in all phases of the research project,^{16,17} including planning, implementation, development of action plans, and dissemination of results.¹⁸ CBPR has been used in prevention studies involving cancer risk among African Americans,¹⁹ sexual health in college students,²⁰ diabetes in American Indian children,²¹ indigenous populations in Ecuador,⁴ families and teachers in an Early Head Start program,²² urban health,¹⁵ heart health,²³ traumatized immigrant children in school settings,²⁴ well-being in rural communities,²⁵ and social determinants of health.²⁶

CBPR has the potential to be especially useful in contexts in which cultural diversity and/or socioeconomic disparities are an issue.²⁷ In minority communities, for example, disseminating evidence-based practices that have been validated on samples made up largely of members of the majority culture can be problematic. Castro et al. described how tension in evidence-based programming has traditionally existed between the fidelity of the implementation and the adaptation of interventions to address the needs of specific groups.²⁸ CBPR can facilitate the fit of interventions to these diverse contexts. As Shiu-Thornton noted, CBPR and cultural competency are largely complementary concepts in that they both “strive to expand knowledge and awareness. Both involve ways of moving and being in the world that embrace a diversity of visions and aspire to translate them into socially responsible, equitable, and humane ways of providing health care and conducting research.”²⁹ Consequently, many researchers have noted how CBPR facilitates culturally grounded prevention programming.³⁰⁻³²

CBPR IN AMERICAN INDIAN AND ALASKA NATIVE COMMUNITIES

American Indian and Alaska Native (AIAN) communities continue to lag behind other minority groups and the majority population on many indicators of health and well-being, including unemployment³³; poverty, education, accidental death, and suicide³⁴; alcoholism³⁵; and health and mental health problems.³⁶⁻³⁹ Perhaps as a result of these disparities, AIAN communities have been the focus of a growing number of national prevention efforts [e.g., the Healthy Nations Project (Robert Wood Johnson Foundation) and the Native American Research Centers for Health (Indian Health Service and the National Institutes of Health)]. However, evidence-based programs developed for the majority culture are often ill suited for the unique historical experiences and cultural diversity of AIAN communities.⁴⁰⁻⁴³ Consequently, there has been a growing emphasis on the development of intervention and research methodologies specifically for use in AIAN communities.⁴⁴⁻⁴⁷

Many of the resulting approaches allow for the acknowledgment of multigenerational historical trauma, including centuries of warfare and other overt violence toward AIAN people, forced relocation and assimilation, and anti-Indian government policies and legal actions. The cumulative effect of these and other experiences reduced the AIAN population to 5% of its size before the European contact.⁴⁸ AIAN scholars have argued that the widespread health and behavioral disparities of AIAN communities must be understood within the framework of intergenerational trauma arising from these historical experiences. When the challenges faced by AIAN communities are viewed outside the historical context of intergenerational trauma, unresolved grief, and loss, they have the potential to be misunderstood and to be addressed in ways that perpetuate the problems.^{49,50} These issues are compounded when insufficient consideration is given to the impact of oppression, discrimination, and disempowerment among AIAN community members.⁵¹ In contrast, collaborations that acknowledge and work within this historical framework have the greatest likelihood of producing lasting change.⁴⁶ Thus, much of the recent work in AIAN communities has emphasized community involvement and the protection of tribal interests throughout the research process.⁵²⁻⁵⁸

CBPR is especially well suited for use in AIAN communities. It allows for the inclusion of community values, cultural heritage, and historical perspective into the prevention activities. As such, CBPR has been employed in many recent AIAN prevention studies.⁵⁹⁻⁶⁸

FROM PRINCIPLES TO PRACTICE: THE TRIBAL PARTICIPATORY RESEARCH MODEL

To facilitate the use of CPBR in AIAN communities as a means of empowerment and self-determination, researchers developed the tribal participatory research model (TPR).^{69,70} As is shown in the Figure, TPR consists of two parallel sets of goals. The first set of goals emphasizes the collaborative process between researchers and community members to develop, implement, and evaluate preventive interventions. The second set of goals involves the establishment of an infrastructure within the participating tribe to conduct future research. These complementary goals are intended to increase community empowerment and self-determination.

Although community participation is an intuitively appealing concept, few guidelines exist for achieving such ends. Other researchers have suggested activities

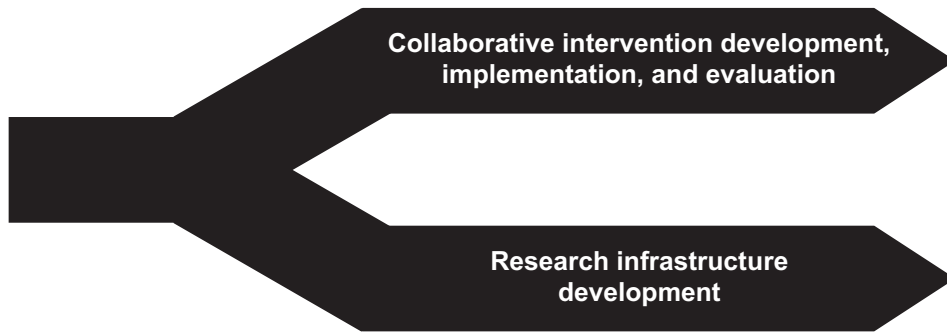


FIGURE. Tribal participatory research conceptual model.

that may facilitate participatory research with AIAN communities, including a preliminary phase of formative research, tribal participation in the Internal Review Board review process, and the ongoing solicitation of feedback from participants.^{42,52,71,72} Similarly, TPR is comprised of four comprehensive mechanisms: (a) tribal oversight; (b) the use of a facilitator; (c) training and employing community members as project staff; and (d) the use of culturally specific assessment and intervention methods. These mechanisms are consistent with core values in AIAN tribes, including tribal sovereignty (i.e., the right of the tribe to conduct business as a sovereign nation on a government-to-government basis), tribal self-governance (i.e., the right of the tribe to conduct governmental affairs), tribal self-determination (i.e., the right of the tribe to set its own course), and tribal consultation (i.e., the right of the tribe to participate fully with the federal government in affairs that involve the tribe and its members). Each of the TPR mechanisms is described in greater detail below.

Tribal Oversight

Tribal oversight should occur throughout the research process. At the outset of the collaboration, before formulating or submitting a proposal for funding, researchers should obtain a formal resolution from the participating tribe's Tribal Council or from another tribal authority. In contrast to nonbinding letters of support from community members or program directors, which are often submitted in grant proposals as evidence of community buy-in to the research project, resolutions carry the legal authority of the tribe. Therefore, they stand to benefit the researcher and the community by documenting a history of understanding about the goals and methods of the research project. Resolutions are especially important early on in the collaborative process, before roles and responsibilities are clearly understood. Researchers should seek additional resolutions after the project is under way, especially if significant changes in the design are being considered, if important decisions need to be made or if ongoing documentation of the collaborative relationship is desired.

Once underway, collaborations should make use of oversight committees that are appointed by Tribal Council or another controlling authority. In contrast to the common practice in CBPR, to employ community advisory boards to offer input into the process, oversight committees have greatly expanded authority, including the ability to approve/disapprove project activities. Oversight committees should include key stakeholders in the community, including Tribal Council members, elders, cultural, religious, and spiritual leaders, and community members who are potential consumers of the prevention services.

To play a meaningful oversight role, regular meetings are essential, especially during the formative research process that frequently precedes the implementation and evaluation of prevention programs. In one TPR project, for example, committees and researchers met more than 70 times during the first 2 years of the collaboration, with consistently high attendance rates among all participants.⁷⁰ Decision-making processes on the committees need to be made explicit, though they might vary by topic. Depending on whether expertise lies primarily with project staff, with committee members, or with both, decisions may be unilateral or shared. The selection of specific cultural practices to employ as intervention components, for instance, should clearly be left in the hands of the tribe. In contrast, decisions about how to analyze or interpret data from the evaluation might be more interactive. For discussions of the processes involved when researchers and oversight committees work together on the analysis of data, see other work by Fisher.^{73,74}

In addition to tribal resolutions and advisory committees, the TPR process is likely to benefit from the establishment of a tribal research code, which legally regulates the research process and specifies the tribe's expectations for researchers, funding agencies, and other governmental agencies.⁷⁵ The model tribal research code was developed by the American Indian Law Center. It contains basic definitions and describes the process for applying for a research permit, the content of the permit application, and the process for enforcing the code.⁷⁶ Because many tribes have research codes in place, researchers should establish whether such a code already exists.

Use of a Facilitator

The participatory process is also supported by the use of a facilitator in meetings involving research staff and community members. A facilitator is especially important early in a project as community members and researchers develop relationships and establish their roles. Facilitators can help to ensure the use of common terminology and can seek clarification when researchers or tribal members do not understand each other. It is notable that CBPR researchers have also recommended the use of facilitators in non-AIAN communities.¹⁸

It can be especially helpful for the facilitator to be an AIAN individual who is known and trusted by tribal members (though not necessarily a member of the participating tribe) and to be familiar with prevention research. The facilitator should be responsible for developing a meeting structure and setting the agenda. It is recommended that meetings embrace general AIAN traditions and tribe-specific traditions (e.g., beginning all meetings with an invocation). It is also helpful for the facilitator to regularly remind researchers that the decision-making process in tribal communities is considerably less linear than in the majority culture and that researchers should put trust in this process.

Community Members as Project Staff

Traditionally, researchers have avoided employing community members as project staff, especially in roles with potential for bias. However, these issues are surmountable given adequate training and development. Furthermore, community members have some strengths as research team members because of their acceptance within and understanding of the community.

As with the oversight process, the training process must involve fairly intensive interaction between potential community research team members and the researchers. Training materials must be accessible to individuals with a range of early educational

experience, and ongoing support and consultation must be provided to solidify skill development. In an earlier project, the research team offered a 1-year, undergraduate-level research methods course for tribal members interested in becoming research team members.^{69,70} The tribal infrastructure created by this course allowed the transfer of all data processing activities from the researchers' institution to the project's reservation-based office, which was staffed entirely with tribal members.

Culturally Specific Assessment and Intervention Methods

In AIAN communities, which typically have close-knit social structures, many conventional methods of prevention science can conflict with community values.^{42,46} This is especially true of designs randomized at the individual level into study conditions. Such disproportionate allocation of resources is inconsistent with a communal orientation that emphasizes sharing. Fortunately, many alternative, scientifically sound designs exist. Perhaps the most straightforward is randomization at the group level. This might be especially useful if the participating community is spread across a large geographic area. Although group randomized designs require larger scale interventions, recent innovations to address problems with intraclass correlations mitigate such problems to a certain degree.⁷⁷

Another quantitative approach that is especially well suited for AIAN communities is the multiple baseline design. This adaptation of a research design for single-participant and small-*N* studies involves gathering data across multiple study sites; the intervention is implemented at each site at time-lagged intervals. Effectiveness is evaluated based on whether changes on outcome variables of interest coincide with each implementation of the intervention. Biglan has argued for the use of multiple baseline evaluations in community-based intervention research in which the prediction and influence over outcomes of interest are not well established.⁷⁸

Finally, many qualitative methods are especially well suited for TPR, including the use of talking circles and semi-structured interviews. These methods are especially useful during the formative research process, when it may not be clear how the community conceptualizes the issues under investigation. In addition, qualitative methods might elicit community members' ideas about outcomes that were not adequately assessed by the quantitative measures.

The TPR approach also emphasizes culturally grounded intervention strategies. This stands in contrast to the practice of adapting evidence-based approaches to obtain cultural competence. Adaptation commonly involves using community members to provide feedback about the cultural acceptability of an intervention. In some instances, the existing intervention content is merely supplemented with materials (e.g., videotapes depicting members of that particular cultural group and/or changes in language). More substantive adaptation can involve altering components of an intervention that may be deemed offensive or incomprehensible by members of a particular group. For minority groups that have experienced oppression, an adapted intervention developed by the majority culture might have several unintended negative implications. For example, it might perpetuate the belief that the community lacks the capability to define and resolve its own problems; thus, the community must adopt foreign concepts and values to address these issues. Additionally, it might suggest that social problems result primarily from individuals' deficits rather than (at least in part) from historical and contextual factors such as intergenerational trauma, poverty, and poor living conditions.^{49,79}

One example of culturally grounded intervention techniques is the reintroduction of storytelling as a positive parenting approach.^{70,80,81} Storytelling incorporates

tribal legends to promote awareness of the natural environment, spirituality, values, and traditional practices. As stories and legends become familiar, they can be used to encourage positive behavior and to discourage negative behavior. Parents can use the stories (and the lessons therein) as teaching tools, addressing their child's problem behavior in a positive, traditional, and effective manner.

CONCLUSION

Lessons Learned and Broader Implications for Prevention Science

In that the TPR model was designed to be flexible and to specify processes (rather than practices) that foster community inclusion in research, it is anticipated that the variations of TPR to emerge for use in other communities and mechanisms and models will continue to evolve as they are applied in such contexts. The three areas believed to have the greatest relevance are detailed below.

Specifying Outcomes Perhaps the most challenging aspect of implementing TPR and other CBPR approaches in the field of prevention is the establishment of a sound evidence base to support interventions. Outcomes commonly employed in investigator-driven intervention programs are inapplicable or of secondary importance to community members. Thus, specifying meaningful outcomes and developing psychometrically adequate measures within these domains can be complex and time consuming.

In addition, changes in the traditional proximal targets of an intervention might not be easily achieved until key contextual factors have been addressed. For example, efforts to reduce child problem behavior through improved parenting might require an understanding about the historical factors that influence parenting practices in the community. In AIAN communities, for example, intergenerational trauma, government boarding schools, and the relocation of families from traditional lands influence parenting. Although such contextual factors might be seen as moderators of intervention targets in the majority culture, they might need to be considered as intervention targets in minority and socioeconomically disadvantaged communities.

Finally, the definition of a meaningful outcome might need to be broadened substantially. Given that many community members distrust researchers and the research process, researchers should determine whether attitudes in this area change as a result of the research process. This topic appears to be receiving increased recognition in the prevention field. In recent published articles, outcomes of CBPR have included perceptions of, satisfaction with, and expectations regarding researchers and research.^{19,21,82} McAllister et al.²² argued for the examining process to be an outcome: "Our goal is to make the practices of CBPR visible and explicit so they can be analyzed, further developed, and effectively applied to a range of public health issues in a diversity of community contexts."

Project Timelines and Resources The timeline for TPR or other CBPR research is likely to be spread over a longer interval than in conventional research because establishing relationships and trust and incorporating the ideals, values, and beliefs of community members are time-consuming activities. Moreover, clearly specifying the roles and responsibilities of those involved is a time-intensive, ongoing task. It takes a considerable commitment for community members to become familiar with

the research principles underlying the work and for researchers to become familiar with the community. In addition, community oversight and research staff training activities are considerably time consuming. Needless to say, the time is well spent if the activities increase the community's acceptance of research to address social problems.

Roles of Researcher and Community Members TPR is characterized by a shift in the roles of researchers and community members. In conventional research, the balance of control favors the investigator, and community members are given circumscribed roles in the decision-making processes. The TPR approach stipulates that researchers make recommendations but generally avoid making unilateral decisions and that the community share control over the data. Given the appropriate mechanisms for facilitating cycles of action and reflection among participants, the approach optimizes opportunities for TPR to effect positive social change.

The TPR approach provides tools for researchers working in AIAN communities that wish to shift away from investigator-driven models of prevention. The approach may also serve as a model for those conducting CBPR in other communities. Although the TPR approach will not supplant traditional methods of prevention science, it might be an effective alternative for improving public health and social change in certain contexts.

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